

## Working Disabled Medicaid

*This program lets individuals with disabilities work and have health care benefits.*

People with disabilities and severe chronic conditions face many barriers to employment. A barrier for many people is the fear of losing their Medicare or Medicaid coverage if they go to work and their disability benefits end. Others are forced to quit work in order to qualify for disability benefits and health care coverage.

Now an Arkansas Medicaid program called "Working Disabled" allows people with disabilities to work, earn a good income, save for the future, and still have Medicaid coverage. Preexisting conditions

are covered, and participants can keep the same coverage if they change jobs.

"Working Disabled Medicaid isn't the only public program that provides health coverage for individuals with disabilities who work, but it's the most flexible," says Scott Holladay, Director of the Employability Project, an outreach effort of the Arkansas Division of Aging and Adult Services. "This program expands opportunities for people with disabilities and severe chronic conditions," says Holladay. "Instead of staying at home, individu-

als can work and support themselves, and still qualify for health care coverage."

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## New Intake Coordinator Arrives

John Breen began his responsibilities as ASCC Intake Coordinator at the end of March 2006. John replaced Bernie Quell who left the

agency in February. The Intake Coordinator is responsible for completing initial assessments and coordinating services on all new referrals in Pulaski County.

John obtained his Masters degree in Social Work at the University of Arkansas at Little Rock and has been an LCSW since 1989. Previous to his employment with ASCC, John worked as a social worker for Hospice Home Care. His background has also included social work responsibilities at inpatient psychiatric care facilities, geriatric day treatment programs and Case Management/Therapist duties at Centers for Youth and Families.

John's twenty-five years experience as a licensed social worker, as well as, working with families in crisis

provide him with much needed skills to be ASCC Intake Coordinator. According to Client Services Administrator Patti Rogers, "John has demonstrated the skills and experience to assist our new referrals and their families in their time of crisis. His exceptional qualifications are an asset to the agency."

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John Breen is the new AR Spinal Cord Commission Intake Coordinator.

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## SPINAL COURIER

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## With Thanks

Donations this quarter from:

**Yvonne P. Balloun**  
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*In Memory of Sandy Scheible*  
**John & Shelley Knight**

*In Memory of Jane Smith*  
**Van Spence**

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

### Check Out UCI's Web Site

Dear Readers:

Recently ASCC client Robert Fitzpatrick of Batesville, AR told me about a web site he thought all people interested in stem cell research should visit. The web site is the University of California at Irvine's Stem Cell Research Center.

He suggested that readers should go to the UCI web site: **<http://stemcell.uci.edu>** and learn more about stem cell facts, download

fact sheets and other educational materials that can be helpful when discussing stem cell research with friends, family and neighbors and sign up for regular e-mail updates.

The UCI Stem Cell Research Center can also be reached by phone at **1-948-824-2911**.

*Dee Welsh, Coeditor*  
*Little Rock, AR*

## From the Director

One of my favorite mantras is "Change is Good." I truly believe that changing things can make them better. For example, we have had a lot of change in staff here at the Commission over the past year. The learning curve is high, when new Case Managers not only try to meet all of their new clients and also learn all about spinal cord injury, spina bifida and multiple sclerosis and all the resources available. It takes a while to get it all done, and while they are doing it, people still need help. You just don't find many people around who know a lot about spinal cord disabilities!

Anyhow, while new folks are going through this process, they ask a lot of questions; often the question is "Why?" Sometimes, in attempting to explain why, we recognize that the reasons don't apply any more, that some things are out-of-date or unneeded. In other cases, they are important concepts and knowing how they came about is useful information.

I know this is true in our agency and I think it is true in many arenas of life. We experience change in many aspects of our lives. Some are easy and fun, some are very hard. But when you face change, ask questions, ask why and share information—you too may decide that change is GOOD!

*Cheryl L. Vines*

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

**AR Spinal Cord Commission**  
**1501 N. University, Suite 470**  
**Little Rock, AR 72207**

## Upcoming SBAAR Family Fest

The Spina Bifida Association of Arkansas (SBAAR) is planning its third annual Family Fest for October 21, 2006, at Camp Aldersgate in Little Rock, AR. The events will include educational sessions for adults and parents and fun activities for children including Halloween crafts and games. Everyone will enjoy a barbecue lunch and recreational programs afterwards. Mark your calendar for **October 21, 2006**.

If there are topics you would like to learn more about or you have suggestions for speakers, please contact SBAAR at **501-978-7222**.

## SAILS Playday at DeGray 2006

Spa Area Independent Living Services (SAILS) and DeGray State Park and Resort are sponsoring their annual Playday Saturday, **August 26, 2006**. The event will take place at the Caddo Bend Swimming Area in DeGray State Park. Come and take part in the many fun activities such as jet ski rides, adaptive skiing, party barge tours of the lake, face painting and bingo. Also, for the daring—meet a snake! Please call SAILS at **501-624-7710** for more information.

## Ms. Wheelchair America Comes to Arkansas

The count down is on! On August 1, 2006, 29 contestants from all over the United States will come to Little Rock, AR for the 32nd Ms. Wheelchair America competition.

The contestants will participate in a variety of events, including a Quilting Day at the Historic Arkansas Museum and Wide World of Sports Day at First Tee of Arkansas, before the judging

begins with interviews and educational programs. Angela Okefor of North Little Rock will represent Arkansas in the pageant.

The public is invited to attend the gala when Ms. Wheelchair America 2006 is crowned on Saturday, **August 6 at 4:00 p.m.** at the Peabody Hotel. Contact Event Chairperson Ida Esh't at **501-296-1635** for additional information.

## White County Support Group Picnic



*Jake Bennett (left), his wife Paula (right) and granddaughter Reese (center) of Judsonia, AR enjoy the food and fellowship, along with around 50 other persons, at the picnic June 6, 2006, held at Riverside Park in Searcy, AR.*

## Nick Masullo Keeps On Writing & Singing His Songs

*Nick Masullo, an award winning songwriter/singer, recently released a CD of his original songs.*



ASCC client Nick Masullo is a songwriter/singer living in Fayetteville. Nick has been writing songs since childhood. He continued writing and, in 2002, Nick was the first place winner of the Woody Guthrie Folk Festival Songwriting Competition. Although he was diagnosed with multiple sclerosis in 2003, he was not sidetracked and was chosen Songwriter of the Year at the 2003 Ozark Music Awards.

The next year Nick was named Best Male Singer-Songwriter at the Northwest Arkansas Music Awards. In December 2005, Nick completed a project he has been working on for the past two years when he had a CD of his original songs released. Some of the songs were influenced by his experiences dealing with his disability. Visit his web site **www.nickmasullo.com** to learn about Nick and his music.



# Autonomic Dysreflexia

By Tom Kiser, M.D., ASCC Medical Director

If you have tetraplegia or a high-level thoracic spinal cord injury, you are familiar with autonomic dysreflexia (AD) and have experienced its effects. If you have paraplegia you may or may not have heard about this phenomenon called AD.

I was discussing AD with a patient and family in clinic the other day. The patient was having a problem with headaches during the bowel program. When I described AD and how it causes headaches and flushing, they wanted to know what other surprises they could expect in the future as they adjusted to life with a spinal cord injury (SCI). This family had been educated about AD before, but head knowledge and actually experiencing AD are two separate things.

When AD first happens to you after a SCI, it can be very scary and worrisome. However, once you come to recognize what is going on, AD can be helpful in letting you know if your bladder is full, if you are due for a bowel program, or if something in your body is wrong and causing pain.

When I am teaching medical students and residents about AD, I describe it to them as a spasm of the sympathetic autonomic nervous system. The autonomic nervous system has two components: 1) the sympathetic system, which raises the blood pressure, speeds up the heart and shuts down the gut to get you ready for activity; and 2) the parasympathetic system, which lowers the blood pressure and turns on the gut to get you ready to relax or to digest your food.

The parasympathetic nervous system control originates from two sites—the brain stem and the sacral spinal cord; however, the sympathetic control originates from the thoracic spinal cord. AD is usually

seen when the spinal cord lesion/injury is above the T6 spinal cord level. It is useful to picture it as a spasm of the autonomic nervous system, because it gives you a good visual picture of what is going on inside your body. Just as a muscle will spasm when stimulated or moved rapidly, the autonomic nervous system can spasm when acutely stimulated by pain.

If you have a SCI above T6, you have very little of the sympathetic nervous system under your control, so if pain occurs due to over distension of your bladder or bowel, the sympathetic nervous system spasms in reflex response and constricts your blood vessels, thus raising your blood pressure. Your brain senses this problem and tries to lower the blood pressure, but has little or no control over the sympathetic nervous system and can only dilate the blood vessels above the SCI and so you get the classic picture of sweating, red and “goose pimples” skin above the SCI due to a dilation of blood vessels and white, dry skin below the SCI due to a constriction of blood vessels. This elevation in blood pressure can be minor with only the consequence of a headache or major with the dire consequence of a stroke.

The treatment for AD is to treat the pain. Once the pain stimulus is gone the symptoms of AD will disappear. This is simple if it is due to the bladder—you empty the bladder by doing an in/out catheter or unclogging the foley catheter. It becomes more complex if it is due to an internal organ such as the appendix or gall bladder.

If you are unable to find the source of the pain rapidly, it is recommended that you lower the blood pressure with medication and get to the emergency room to determine the cause of pain. Do not be surprised if the emergency room



*ASCC Medical Director Tom Kiser, M.D.*

physician is unaware of AD and the consequences of elevated blood pressure and possible stroke. With all the information a physician has to learn, this is an area of medicine that he does not see very often, so if he was taught about it, he has probably forgotten and you are possibly the first case he has ever seen. Doctors are taught that common things happen commonly and they have a hard time thinking outside of the box of what they know.

So I suggest that you always carry your AD card provided to you by the Spinal Cord Commission. This will alert the nurse and the physician in the emergency room about your condition and give them the recommended method of treatment. After the workup is started then they can learn about AD and you can use this as a teachable moment for the health care professionals in your community.

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## John Breen

*Continued from page 1*

John enjoys working with children and does a lot of volunteer work with Big Brothers/Sisters of Central Arkansas and Kaleidoscope Kids. John is also a member of the Knights of Columbus where he serves as their Youth Director.

The Arkansas Spinal Cord Commission feels very fortunate to have someone with John's background and experience. Please join the Commission members and staff in welcoming John to our agency!



# Smoking and SCI

By Judith Elmore, C.R.R.N., C.C.M.

If this article inspires even just one person to quit smoking, it will have been worth the review, writing, editing, printing, and reading.

Smoking is a personal and difficult—some say impossible—habit to kick. Besides the physical addiction, psychological reasons also lead to dependency on and addiction to tobacco.

Past and present smokers know their reasons *for* smoking and those that enabled them to *stop*. It would be wonderful if one solution would help everyone, but we know this is not the case. This article discusses some physical reasons why people with spinal cord injury (SCI) who smoke have increased risks for heart disease, stroke and cancer.

Why should you be more concerned than people without SCI? Other issues specifically concern individuals with SCI, and you need to know these in order to make intelligent decisions about your health and lifestyle. Understanding the negative effects about smoking and SCI will allow you to make an informed decision.

According to the American Lung Association (November 2004), smoking-related diseases claim an estimated 440,000 American lives per year. Cigarette smoking contains more than 4,800 chemicals, 69 of which are known to cause cancer. The Environmental Protection Agency (EPA) has classified secondhand smoke as a known cause of cancer in humans (group A carcinogen). It causes about 3,000 lung-cancer deaths and 35,000 heart-disease deaths each year in the United States in adult *nonsmokers*.

## Breathing

The human respiratory system is the miracle that keeps us alive. It is made up of spaces, muscles, cavities, tissues, lymph nodes, blood membranes, cilia, mucus, and air sacs and cells. The lungs (organs) provide a “station” where oxygen taken into the body can be infused into the bloodstream and distributed to all other organs and tissues in the body. In one day, the lungs take in 8,000-9,000 liters of air (oxygen) and exchange with 8,000-10,000 liters of blood pumped through the heart to remove waste and refresh the blood with oxygen.

The lungs are constantly exposed to the environment, which contains pollen, dust, bacteria, viruses, spores, and all types of potentially toxic chemicals including car and bus fumes. At home, you may even be exposed to dangerous toxins or irritants like radon, lead, household chemicals, and even animal dander.

*If you have SCI and you smoke, find out everything you can about the harmful effects of smoking, including secondhand smoke.*

Add to these invaders the cigarette smoke you choose to place in your body (or secondhand cigarette smoke, about which you have less choice) and an SCI, and perhaps you can begin to understand how harmful this combination can become.

What else can smoking or secondhand smoke do to someone with SCI? It further reduces the lungs’ total capacity (already decreased by weakened or absent muscles due to SCI). This impairment could lead to a buildup of mucus and other secretions in the lungs. Then if you go outside and are exposed to environmental toxins, who knows what can happen? It provides a breeding ground for a variety of infections.

Smoking accelerates the naturally occurring process of decreasing elasticity in the lungs and muscles of the chest wall.

## Skin

As stated above, decreased lung capacity will lead to lower amounts of oxygen circulating in the blood. This has a direct effect on the healing process. The skin is the body’s largest organ. Healthy skin depends on oxygenated blood bringing nutrients to it. Less oxygenated blood and nutrients combined with the decrease of removing the waste products provides a good “atmosphere” for developing pressure ulcers. Add lack of weight shifts, tight clothing, shearing, or friction and you increase your chances of developing a sore.

The relationship between smoking and impaired healing is well documented. As a matter of fact, the healing time is longer, and it appears that smoking not only helps you develop pressure ulcers but also helps you *keep* them.

## Bones

Due to metabolism changes, people with SCI begin bone loss immediately after injury. This loss can continue for 6-16 months after injury. It often leads to *osteoporosis*. This bone disease due to a loss of minerals increases the chance of fractures. Cigarette smoking reduces the body’s ability to absorb calcium; this can lead to or accelerate bone loss.

## Bladder

Numerous studies over the years have shown bladder cancer is related to smoking, as cancer-carrying agents may be present in the urine. Indwelling catheters have been found to increase the risk of bladder cancer 3.8 times, compared to non-indwelling catheter users. Aging people with SCI who have used indwelling catheters for a long time have an added risk of developing bladder cancer. The risk of bladder cancer among those with SCI is about 3% compared to less than .001% for the general public.

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# Up Close and Personal: Susie Kirkwold

*This is the eleventh in a series of articles profiling the ASCC Case Managers.*



Susie Kirkwold joined the ASCC Little Rock Case Management office in February 2003. She currently provides services to individuals in Lonoke, White and part of Pulaski County. After spending three years providing case management services to individuals with spinal cord disabilities Susie stated, "One of the most important things I have learned is just how strong my clients are and, in fact, in many aspects they are a lot stronger than I am."

Susie holds a Masters degree in Counseling from Henderson State University. Although a native of Hot Springs, Susie spent five years in Tulsa, OK working in mental health and with disadvantaged students prior to returning to the state. The Commission was very pleased when she decided to return home and join ASCC.

Client Services Administrator Patti Rogers commented, "Susie is very tenacious and a great advocate for her clients. She works hard to locate services and meet her clients needs." In addition to her normal duties she facilitates a support group in Searcy and also assists with the support group in Sherwood.

Susie lives in Maumelle. When not at work, you will find her spending time with her friends, reading and writing.

## **PROFILE:**

**Date And Place Of Birth:** January 28, 1971, in Seattle, WA

**Family Members:** My parents, Larry and Arlene, live in Hot Springs; my brother, Tom, and his wife, Lisa, live in Arkadelphia along with my nephews, Evan and Trevor. I live in Maumelle with my dog, Huck, and recently acquired cat, Amelia.

**If I Did Not Live In Maumelle, I Would Want To Be:** In Northwest Arkansas

**I Absolutely Will Not Eat:** Liver—in any form

**One Thing People Would Find Surprising About Me Is:** I want to be a mother, preferably a wife and mother; but definitely I will have a child of my own someday

**My Favorite Movie Is:** *The Color Purple*

**My Favorite Song Is:** *American Pie*

**I Am Most Comfortable With People Who:** Are comfortable with themselves

**My Favorite Pastimes Are:** Reading, walking/hiking, spending time with friends and family

**The Best Advice I Ever Received Was:** "Let your heart be a guide, but FOLLOW your mind."

**My Favorite Saying Is:** "Once bitten, twice shy"

**I Knew I Was Grown Up When:** I started paying mortgage in lieu of rent

**The One Thing I Always Wanted To Do But Have Never Had The Chance Was:** Meet my grandmother, Cora

**One Word To Sum Me Up:** Blunt



# Smoking and SCI

Continued from page 5

## What To Do

Smoking can affect your bones, may cause pressure ulcers and their slow healing, or even contribute to bladder infections.

But smoking is your choice, right? What about your significant other, your family, and your friends smoking around you—and their secondhand smoke? Are they controlling or contributing to your future, too?

If secondhand smoke contributes negatively to your lifestyle, why is *your* smoking not harmful? I believe you know it *is*. You must make up your mind to take control.

If you have SCI and you smoke, find out everything you can about the harmful effects of smoking, including secondhand smoke. It is ultimately *your* decision, but please be as informed as you possibly can.

When you choose to quit, don't be afraid to ask for help from your healthcare providers, family, friends, or clergy. Consult your

healthcare providers for the assistance available in your area.\*

Contact: [JudyE@pva.org](mailto:JudyE@pva.org)

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\* Persons in Arkansas who need help quitting use of tobacco should contact the Arkansas SOSQuitline toll free at: **1-866-NOW-QUIT** (669-7848) or online at: [www.uams.edu/coph/tobacco/QuitlineHome.asp](http://www.uams.edu/coph/tobacco/QuitlineHome.asp)

## Don't Miss ADSA's Hunts this Year!

The Arkansas Disabled Sportsman Association (ADSA) will be sponsoring a variety of deer, duck and turkey hunts this year.

If you want to take part in the 2006–07 hunts organized by ADSA, please contact Toney LeQueieu, Russellville ASCC Case Manager at **479-890-5751** or you can e-mail him at [tlequeieu@arspinalcord.org](mailto:tlequeieu@arspinalcord.org) by Friday, **August 25, 2006**. Don't be left out of the ADSA hunts this year!



ASCC Commissioner Jimmy Ashley and his hunting companions prepare to leave after a successful ADSA sponsored duck hunt.

# Working Disabled

Continued from page 1

Holladay says the program is intended for people with severe disabilities who support themselves by working. The Working Disabled program was launched five years ago, but few people know about it, even those who provide disability services.

To qualify for Working Disabled, an applicant must meet these criteria:

- Ages 16 through 64.
- Have a severe disability or chronic condition expected to last one year or longer, based on Social Security disability guidelines. Unlike Social

Security Disability, applicants may work full-time.

- Work and have work income reported to the IRS. Applicants may be self-employed or employees.
- Receive little or no unearned income, such as Social Security, SSI, VA, etc.
- A single applicant can earn up to about \$4,000 per month, if all income is from work. Applicants with a spouse or children under 18 at home can earn more. The spouse's income is not counted.

For more information about Working Disabled eligibility, or to find out how work will affect your disability benefits, call the Employment Sources Hotline. The toll free

hotline number is **1-866-283-7900**. The hotline can also help individuals with disabilities arrange other employment-related services.

To apply for Working Disabled, individuals should contact their local county Arkansas Department of Health and Human Services (DHHS) office.

Working Disabled Medicaid covers only working individuals with disabilities, and family coverage is not included. Medicaid covers home and community services, such as personal care, as well as medical services. If an individual has both Medicare and Medicaid, Medicaid will pay the premiums, deductibles, and co-pays for Medicare Parts A, B, and D.



# The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you “should have done but didn’t.”

Pat Cole of Harrison, AR suggested that we all learn from her mistakes. Here is her lesson number one:

Back in September 2003, I had a small pressure sore on the side of my foot. Per doctors orders, I was using a heat lamp on it twice a day. It was nearly healed and one day while I was in bed I propped my foot on a pillow so the lamp could hit the correct area. The allotted time limit was up and I looked

down to turn the lamp off. My foot had somehow slid off of the pillow and the side of my foot was resting directly on the lamp!

I knew immediately that a bad thing had happened. I slowly removed my support hose and saw two yellow waxy toes. I called

my doctor and he told me to come right in. He then sent me directly to the hospital. The next day, two of my toes were amputated.

Lesson number one: **If you have to use a heat lamp, be extremely careful with it!**

**We invite you to send in your helpful hint**—your bit of “grease.” Contact your ASCC Case Manager, write us at *Spinal Courier*, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at [courier@arspinalcord.org](mailto:courier@arspinalcord.org)

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